



FEDERAL CAREGIVERS

US Administration on Aging

Regions I, II & III May 2002

On the morning of September 11, 2001 a gentleman who was the primary caregiver of his invalid mother, dropped her off at an adult day care center in Washington and proceeded to work at the Pentagon. This was his regular routine to ensure quality support and care for his mother, taking advantage of available community services, while he continued to fulfill his duties as a Federal employee. Unfortunately, this man never returned to pick up his mother as he was killed in the plane crash into the Pentagon. The adult day care center responded, not only in caring for the mother that day but also in arranging for in-home respite for the mother for the next seven days. That allowed the family time for mourning and time to plan and arrange for other care for the mother.

The gentleman, as a significant caregiver for his mother, is not unique among Federal or other employees. In fact, caregiving employees comprise almost one-third of any employee group. Yes, you may be one of every third employee who has some level of responsibility to care for an aging relative. It is often you, an adult child, providing significant help to one or both of your parents or you caring for your impaired spouse. Perhaps it is you, a grandchild assisting your grandparents or you aiding a sibling, another relative or even you caring for a loved one, a friend or a neighbor.

Many persons don't even recognize their role as a caregiver. If you are helping an older family member or a friend who can no longer manage... if you help with daily needs like bathing or dressing... if you help balance their checkbook...if you take the person to the doctor or the grocery store... **then you are a caregiver.**

Caregivers provide a wide variety of supports from routine, straight-forward tasks to the most complex. Responsibilities naturally increase over time. You may start out doing some transportation, yard work, household chores, shopping or filling prescriptions. Then you have to pay bills, manage finances and provide meals. As older persons decline the responsibilities and the intensity of your responsibilities increases. You may have to provide personal care including dressing, feeding, bathing, toileting and transferring. The burdens increase to the point that 24 hours, 7 days a week of your assistance may be required.

While you may not be a caregiver today chances are that at some point you will be. It is important that you know, as did the Pentagon employee, that there are resources available to assist you in dealing with the burdens associated with caregiving. We, the staff of DHHS' [Administration on Aging](#) (AoA) covering the Boston, New York and Philadelphia regions, would like to provide you with some information on caregiving as part of our recognition of May 2002 as Older Americans Month.

AoA supports a Network of State Unit and Area Agencies on Aging as well as thousands of community agencies that provide a wide range of supportive services to older persons and their families. Our goal is to maintain the independence of individual older persons in their home settings. The Network manages services such as meals-on-wheels, nutrition sites, transportation, case management, personal care, adult day care, information and referral, etc.

The following information has been grouped into three major sections:

🍷 Caregiving and the Workplace

🍷 Caregiving and Supportive Services

🍷 Where to Turn for Help – Resources to Contact

CAREGIVING AND THE WORKPLACE

According to a recent survey, over seven million people are informal caregivers, i.e., spouses, adult children, or other relatives and friends who provide unpaid help to older people at home who have limitations. A significant number of these caregivers are, like you, employed outside the home. In fact, almost one-third of the workforce today is caring for an elderly relative or friend while balancing the demands of both. The cost implications to the country as well as to the employer of the potential breakdown of caregiving are extraordinary.

Caregivers dedicate on average 20 hours per week providing care for older persons, and even more when the older person has severe disabilities. The cost to caregivers in terms of time, physical and emotional stress, and the financial burden can be significant. To help alleviate these burdens, caregivers need information and assistance to identify and use community services, acquire

personal care skills and understand the psychological and medical problems associated with aging and caregiving.

The employment status of caregivers is directly related to the level of care provided to the elderly. Most employed caregivers must make accommodations in their work schedules in order to meet their responsibilities. In fact, studies have pointed to a number of factors relating to the impact of caregiving on workers, such as:

- ❖ Two-thirds of working caregivers report conflicts between work and caregiving. Tardiness and absenteeism may become problems.
- ❖ Caregivers often need to rearrange their work schedules, work fewer than normal hours and/or take unpaid leaves of absence. This results in an interrupted workday.
- ❖ Many caregivers report mental health problems as a result of caregiving, and often have to turn down promotions or terminate employment.
- ❖ Physical and emotional health indicators of stress, such as depression, cause over utilization of sick days.
- ❖ Health care costs for the wage earner's spouse and other dependents in need of care can be greatly re-

duced when care is provided by a family member.

Workers often do not plan for how and when they will assume a caregiving role, nor know where to turn for help, and are confronted with the resultant overload when a family member needs care. Furthermore, working caregivers have little, if any, knowledge about resources available in their community to help them in their caregiver role and are not prepared when emergencies arise. While national recognition has been paid to the unique role of families in the provision of caregiving through the Family and Medical Leave Act and the new National Family Caregivers Support Program, the growing need to assist employees who provide caregiver support remains a challenge.

CAREGIVING AND SUPPORTIVE SERVICES

Family caregivers are the invisible backbone of the American healthcare system. More than one quarter (26.6%) of the adult population has provided care to a family member or friend during the past year (A National Family Caregivers [NFCA] Association survey).

Based on current census data, that translates into more than 54 million people. Of that, an estimated 19% of families in the U.S. may be

caring for an adult with cognitive impairment. These impairments include a variety of diseases and disorders (i.e., Alzheimer's disease, Parkinson's disease, stroke, head injury or AIDS dementia). The NFCA survey revealed a number of other surprising facts:

Male/Female Ratio - The male/female ratio involved in caregiving has changed dramatically. Caregiving was considered a women's issue on the basis of data that had shown that women provided 75 percent of "family" care. The new survey shows a much more even split: 56 percent female, 44 percent male.

Type of Care - 52 percent of survey respondents provided physical care. They rolled up their sleeves to help loved ones in need of personal assistance, including helping them with dressing, bathing, toileting, eating and mobility.

46 percent of respondents were involved in performing some type of nursing activity such as managing medications, changing dressings, or monitoring vital signs.

Economic burden - 54% of family caregivers are between 35 and 64 years old. Tending to a friend or relative during these key wage-earning years takes a toll on the financial well-being and earning potential of these workers.

Caregiving can be complicated. Finding resources and making key deci-

sions is not an easy task. The entire family needs to address caregiving issues. Some caregivers are reluctant to acknowledge the strain related to the many tasks, responsibilities and long hours they devote to providing care.

Many feel overwhelmed or burned out. They find it hard to credit themselves for the work they are doing as a caregiver. Most fail to arrange for some support to take an occasional break from daily duties.

Some tasks can ignite or magnify family conflicts, especially when various people cope differently with their caregiving responsibilities. Family members may deny what is happening, resent members for living far away, or believe some members are not helping enough. There may also be disagreement about financial and care decisions. Minimize these conflicts by trying to acknowledge these feelings and work through them together with other family members.

Financial and legal planning are important needs to consider. Issues such as financing long-term care, protecting assets, obtaining the authority for surrogate decision making (i.e., Advance Medical Directives and Durable Power of Attorney for Health Care) will often need an attorney's attention. Decisions about housing, physical needs, and after

death provisions also need to be considered.

Decisions about placement in a nursing home or other care options can often be helped by a person familiar with physical impairments, caregiving and community resources such as a case manager.

Many caregivers report that they frequently experience high levels of stress, and nearly half say they suffer from depression. Many caregivers don't recognize their needs, fail to do anything about them, or simply don't know where to turn for help. Recognizing the signs and learning how to reduce stress can help.

Warning signs of caregiver stress include: denial, anger, social withdrawal, anxiety, depression, exhaustion, sleeplessness, irritability, lack of concentration and health problems. If you are a caregiver experiencing several of these stress symptoms on a regular basis, consult a physician and/or seek appropriate services.

SUPPORTIVE SERVICES

Facing these caregiving tasks can be a monumental challenge. But increasingly there is a range of community supportive services to assist you in meeting the challenge:

Information services can lead you to the right place or service..

Care management services can assess a person's needs and resources, draw up a plan in conjunction with the family and help you secure necessary services.

Support groups enable you to share practical information, solve problems, support each other, and learn new ways of coping.

Training can prepare you for the tasks you have never before done, such as personal care at home.

Respite care provides you temporary relief from tasks associated with caregiving. Respite is mainly offered through community organizations or residential facilities. The most common respite care programs are in-home care and adult day services.

In-home services offer a range of options, including companion services, personal care, household assistance, and skilled care services to meet specific needs.

Adult day services (ADS) provide opportunities to interact with others, usually in a community center or facility. Transportation and meals are often provided. Frequently ADS gives you a break, some respite and/or enables you to be a working caregiver.

Supplemental services complement the care you provide and essentially fill in what-ever else may be needed to

keep the caregiving arrangement together. Some common supplemental supports are: personal emergency response systems, i.e., an electronic device that allows older persons at-risk to secure help in an emergency; transportation; and home modification and maintenance, i.e., ramping access to a home or widening doorways for wheelchairs.

Hospice programs provide care to terminally ill persons. This service is available through local hospice organizations and some home care agencies, hospitals, and nursing homes. Once a doctor has determined that a person is in the terminal phase of a disease, he or she may be eligible for Medicare benefits.

GRANDPARENTS PROGRAM

At a time when most grandparents are well past their child-rearing days, some have become primary caregivers of their grandchildren age 18 and under. They need support to manage issues such as stress, custody, health care, income supports, education, etc. Grandparent caregivers need information, peer support and respite as well.

NATIONAL FAMILY CAREGIVERS SUPPORT PROGRAM

Where then do you as a caregiver turn to get information about these and other supports? There are many resources noted in the

next section. Significant among them is the Aging Network of State and Area Agencies on Aging and their contractors that receive funding from AoA. In 2000 Congress established the National Family Caregivers Support Program (NFCSP) in recognition of the tremendous investment of time and effort that informal caregivers have made that needs to be bolstered with community supports. The program, administered through the State Agencies on Aging, which you can internet link to in the next section, includes five components:

- ❖ Information to caregivers about available services;
- ❖ Assistance to caregivers in gaining access to supportive services;
- ❖ Individual counseling, organization of support groups and training;
- ❖ Respite care to enable caregivers to be temporarily relieved from their responsibilities; and
- ❖ Supplemental services to complement the care provided by caregivers.

In addition to serving the needs of family caregivers of those over the age of 60 years, a portion of the funding allocated to States can be dedicated to supporting grandparents caring for grandchildren.

WHERE TO TURN FOR HELP RESOURCES TO CONTACT

There are two levels of caring involving you as a caregiver. One is caring for yourself. The other is the care you need to provide for the person you are caring for. You must take care of yourself in order to be able to care for your loved one. Thus, we have divided this Resources section to address both your needs as a caregiver and the needs of the person you are caring for.

Information & Services For You As A Caregiver

Available on the Administration on Aging's web site (www.aoa.gov) is a link to our "*National Family Caregiver Support Program*." Designed to help our national aging network to develop caregiver support programs, you can also access our link to the "*Caregiver Resources for Older People and Families*." At this site, you will find information about your role as a caregiver and where to turn for help. Here you can find a variety of links to other government, non-profit and commercial sites designed to address your needs and concerns as a caregiver.

Click on "*Because We Care – A Guide for People Who Care*." This *Guide* is an excellent start for information and suggestions to understand your role as a caregiver and to answer general questions you might have. You can access the *Guide* directly at the following website:

www.aoa.gov/wecare/default.htm

To find out about specific caregiver programs and services available in your State and community, here is a listing of contacts in the State Agencies on Aging in our Regions. They can provide you information about what is available state wide and can direct you to the appropriate agencies/organizations within your own commu-

nity that provide programs and services for you as a caregiver.

REGION I

CONNECTICUT

Department of Social Services
Elderly Services Division
Donielle Long donielle.long@po.state.ct.us
860-424-5862

MAINE

Bureau of Elder & Adult Services
Mary Walsh mary.walsh@state.me.us
207-624-4348

MASSACHUSETTS

Executive Office of Elder Affairs
Michael Banville
michael.banville@state.ma.us
617-222-7477

NEW HAMPSHIRE

DHHS Division of Elderly & Adult Services
Sandra Malasky smalasky@dhhs.state.nh.us
1-866-634-9412

RHODE ISLAND

Department of Elderly Affairs
Kathy McKeon kathy@dea.state.ri.us
401-222-2858 ext. 202

VERMONT

Department of Aging & Disabilities
Camille George camille@dad.state.vt.us
802-241-2400

REGION II

NEW JERSEY

Division of Senior Affairs
Barbara Fuller
barbara.fuller@doh.state.nj.us
609-943-3463

NEW YORK
State Office for the Aging
Nick Rogone
nick.rogone@ofa.state.ny.us
518-474-8388
Andrea Hoffman
andrea.hoffman@ofa.state.ny.us
518-474-0484

PUERTO RICO
Governor's Office of Elderly Affairs
Wanda Aquino
waquino@ogave.gobierno.pr
787-721-6121

VIRGIN ISLANDS
Department of Human Services
Eva Williams dhs@islands.vi
340-774-0930

REGION III

DELAWARE
Division of Services for Aging & Adults
with Physical Disabilities
Leah Jones leahjones@state.de.us
302-577-4791

DISTRICT OF COLUMBIA
Office on Aging
Sherlyn Taylor sherlyn.taylor@dc.gov
202-727-8371

MARYLAND
Department of Aging
Stephanie Garrity
sag@mail.ooa.state.md.us
410-767-1112

PENNSYLVANIA
Department of Aging
Dan McGuire dmcquire@state.pa.us
717-783-6873

VIRGINIA
Department for the Aging
Cecily Slasor aging@vdh.state.va.us
804-662-9338

WEST VIRGINIA
Bureau of Senior Services
Jan Bowen jbowen@boss.state.wv.us
304-558-3317

Where To Get Help For The Older Person You Are Caring For

As a caregiver, one of your first concerns is to try to address the needs and issues of the older person you are caring for. We have a ***national aging services network*** (composed of the Administration on Aging, State Agencies on Aging, Area Agencies on Aging and local community service providers) to assist older people and their caregivers.

This network provides a wide range of services including nutrition, transportation, senior centers, health promotion, home-maker, chore, case management, personal care, nursing home ombudsman program, legal assistance, elder abuse prevention, information and assistance, public benefits and insurance counseling.

To find out about the services and programs in your state, access the web site of the State Agency on Aging or call at the number listed below. They can tell you about the programs available statewide and direct you to the appropriate Area Agency on Aging where specific local services and programs can be found.

CONNECTICUT
DSS-Elderly Services Division
www.ctelderlyservices.ct.us/
1-800-994-9422 860-424-5298

DELAWARE
Division of Services for Aging & Adults with Physical Disabilities
www.dsaapd.com/index.htm
1-800-223-9074

DISTRICT OF COLUMBIA

Office on Aging

www.dcoa.dc.gov/

202-727-8368

MAINE

Bureau of Elder & Adult Services

www.state.me.us/dhs/beas/

207-624-5335

MARYLAND

Department. of Aging

www.mdoa.state.md.us/

410-767-1100

MASSACHUSETTS

Executive Office of Elder Affairs

Site under construction

617-727-7750

NEW HAMPSHIRE

DHHS – Div. of Elderly & Adult Services

www.dhhs.state.nh.us/index.nsf?open

603-271-4680

NEW JERSEY

Division of Senior Affairs

www.state.nj.us/health/

1-800-792-8820

NEW YORK

State Office for the Aging

www.aging.state.ny.us/

1-800-342-9871 518-474-7158

PENNSYLVANIA

Department. of Aging

www.aging.state.pa.us/

717-783-6873

PUERTO RICO

Governor's Office of Elderly Affairs

Web site under construction.

787-721-6121

RHODE ISLAND

Department. of Elderly Affairs

www.dea.state.ri.us/

401-222-2858

VERMONT

Department of Aging & Disabilities

www.dad.state.vt.us/

802-241-2400

VIRGIN ISLANDS

Dept. of Human Services

Web site not available.

340-774-0930

VIRGINIA

Dept. for the Aging

www.aging.state.va.us/

1-800-552-3402 804-662-9333

WEST VIRGINIA

Bureau of Senior Services

www.state.wv.us/seniorservices/

304-558-3317

If you are caring for someone outside of the states in our Regions, contact the **Eldercare Locator** at 1-800-677-1116 or on the web at www.eldercare.gov/. The nationwide toll-free number will link you to the Information & Referral (I & R) services of the appropriate State and Area Agency on Aging. These I & R programs can help you identify the local services in the area where the person you are caring for resides.

Information and questions about **Medicare** can be addressed via the web at www.medicare.gov or by calling 1-800-MEDICARE (1-800-633-4227).

For information and questions about **Social Security** benefits and services, you can access their web site at www.ssa.gov or call 1-800-772-1213. .

As noted the National Family Caregiver Support Program includes a component for **“Grandparents Caring For Children”** eighteen years or under. In addition to information states may have on grandparent programs, additional information can be found on the web site of the **Brookdale Foundation. Relatives As Partners Program.** www.brookdalefoundation.org

General information about aging services is available on our web site at www.aoa.gov. You can also call us at the Boston and New York Regional Office at 617-565-1158 (Region I) or .212-264-2977 (Regions II & III)

In preparing this Caregiver Newsletter we reviewed a number of resources from other organizations including those listed above as well the Alzheimer's Association www.alz.org and the National Family Caregivers Association www.nfcacares.org. We appreciate and acknowledge them.

In conclusion, to you the Federal employee who reads this Newsletter, we hope it will make the difficult and valuable job of caregiving a little easier. For those of you who may be caregiving in the future we hope you will find it a useful reference.

Thank you!

**Regional staff of the
Administration on Aging.**

Gene Brown
Joseph Carlin
Noreen Headle
Barry Michaels
Lou Levitz
Bob O'Connell
Jerry Perlman
Carmen Sanchez
Patricia Treacy
Legan Wong



**Older Americans Month
May 2002**

"Older Americans are the heartbeat of our communities, and they give us the energy and motivation to move forward and contribute to our nation's strength, success and prosperity."

Josefina G. Carbonell
Assistant Secretary for Aging

